



# HIDDEN FROM VIEW:

## Community Carers and HIV in Rural South Africa

**BACKGROUND INFORMATION**



**SENZOKUHLE CBO NETWORK**

**AMNESTY  
INTERNATIONAL**



Image: Two carers walk towards a homestead, KwaZulu-Natal Province, June 2011. © Gille de Vlieg

## **HIDDEN FROM VIEW: Community Carers and HIV in Rural South Africa**

*“Being a carer comes from loving or having a passion for working with the community.”* (Thandi Mdletshe, carer)

*“If someone comes and is hungry and I know they are on antiretrovirals, then the first thing I will do as a home-based carer is to cook for them and give them food, then they can start talking about other problems.”* (Ma Gwala, carer)

*“When someone who asks me for money for transport, I might not be able to give them the 16 rands for a shared taxi, but I might be able to give them 11 rands for the bus.”* (Sihle Xulu, carer)

*“People are grateful for the work that we do....we sit with them and talk and encourage them to go to the health facility. You can see when they start treatment they are burdened, but after some time, they get better, they get fat”.* (Nelisiwe Masondo)

Over the past two decades the HIV epidemic has had devastating effects on the health and well-being of communities in South Africa. However in the last several years, access to life-saving antiretroviral treatment (ART) and care through state and non-governmental programmes has expanded remarkably. By 2011 some 1, 500,000 people had been initiated on ART. Both the improved ability of people living with HIV to maintain their health and stronger government leadership have helped reduce social discrimination.

However challenges remain. People living in rural areas still struggle to gain access to the food and services they need to maintain their health because of poverty and because they live in remote areas. In addition, women’s ability to protect their health continues to be affected by discriminatory practices, economic marginalization and violence. The South African government has an obligation to ensure that there is no discrimination in access to health services as part of making the right to health a reality.

Senzokuhle CBO Network and Amnesty International<sup>i</sup> have collaborated to develop a photo-story exhibition to help increase recognition of the importance of community-based care work in supporting people living with HIV. The carers, whose photographs and testimonies feature in this exhibition, come from three, predominantly rural, health districts in KwaZulu-Natal province where the network operates. KwaZulu-Natal is the province most affected by the HIV epidemic, with approximately one-quarter of 15-49 year-olds and nearly 40 percent of women attending ante-natal clinics infected with HIV.<sup>ii</sup> The exhibition, which will be shown in Eshowe, Soweto, Durban, and possibly in other areas, is intended to contribute to a wider civil society campaign urging the government of South Africa to ensure that community-based and often unpaid care work is valued and resourced. Amnesty International and Senzokuhle CBO Network believe that this will strengthen the state’s efforts to meet its obligation to ensure non-discriminatory access to health services.

In September 2011 Amnesty International made a submission with recommendations for consideration by the South African National AIDS Council for the new National Strategic Plan for HIV and AIDS (NSP). The organization welcomed the open, co-operative and consultative process across government and non-governmental sectors to develop the next five-year plan.<sup>iii</sup> In respect of the multiple forms of discrimination affecting access to HIV-related health services in rural areas, Amnesty International acknowledged the enormous progress made in the last two years and impact of increased clinic-level access to ART, along with the promotion of models of “down-referral” of patients and “task-shifting”, including the roll-out of nurse-initiated and managed ART capacity in clinics. It also acknowledged that these improvements, which have helped increase access for remote and poor communities, have been associated with the roll-out of new guidelines allowing earlier beneficial access to ART including for HIV-positive pregnant women.

Amnesty International, however, noted in its submission a concern that both physical and economic barriers to access to health services continue to affect poor, rural households. An important aspect of the problem is the apparent lack of improvement in transport systems and road infrastructure in rural communities. Amnesty International's own research and information from wider consultations indicated that access is still affected by the cost of transport for households reliant on welfare grants or precarious informal sector income; the conditions of subsidiary roads impassable to emergency vehicles or group taxi vehicles; and the infrequency and unreliability of public transport.

These circumstances appear to affect decision-making by poor households/individuals regarding seeking or keeping medical appointments, including for referrals to more distant facilities. They continue to require the borrowing of money for transport costs where repayment is often unfeasible. Access to or adherence to treatment also remains affected by the lack of availability of food for poor rural households, along with arbitrary processes and decision-making regarding eligibility for disability grants.

These circumstances and concerns are highlighted in Hidden from View, through the voices of the carers and some of those assisted through their work.

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<sup>i</sup> The Senzokuhle community-based organization (CBO) network of carers, some of whom are featured in the Hidden from View exhibition, is located in KwaZulu-Natal province. It seeks to raise awareness of the barriers faced by women living with HIV in their communities in making their right to health a reality. Amnesty International has campaigned locally and internationally since 2008 for action to overcome the barriers to the right to health in South Africa (see for instance the report '*I am at the lowest end of all*' *Rural women living with HIV face human rights abuses in South Africa*, <http://www.amnesty.org/en/library/info/AFR53/001/2008>). The work, including the exhibition, is part of the organization's global Demand Dignity Campaign, which seeks to enable people living in poverty to claim their human rights.

<sup>ii</sup> The content of the exhibition was put together by the two organizations along with the carers through a participatory and informed-consent process. Where the exhibition includes photographs or testimonies of members of households who have been assisted by the carers, their identities have been withheld. They were photographed under conditions agreed to by the particular individual and after discussion with their care-giver. For more information about the exhibition contact Senzokuhle ([info@senzokuhle.org.za](mailto:info@senzokuhle.org.za)); Amnesty International South Africa ([Jacqueline.khumalo@amnesty.org.za](mailto:Jacqueline.khumalo@amnesty.org.za))

<sup>iii</sup> Submission to the SANAC Secretariat on Draft Zero of the National Strategic Plan for HIV and AIDS, STIs and TB, 2012-2016 from Amnesty International (including Amnesty International South Africa)